

SIC ECHO Updates & Innovations Series

Serious Illness Conversation Training for Facilitators & Clinicians Essential Conversations, Talking to Parents Whose Seriously Ill Adult Child Cannot Speak for Themselves

Thursday, September 21st, 2023, 1:00pm – 2:00pm PST, via Zoom

AGENDA ITEM	DISCUSSION	RESOURCES
Introduction & Territory Acknowledgment	<p>Serious Illness Conversations training for facilitators and clinicians: Essential Conversations, Talking to Parents Whose Seriously Ill Adult Child Cannot Speak for Themselves</p> <p>Welcome to all participants, and introduction of the presenter, and presentation outline. Participants are notified the session is being recorded.</p>	
Overview Summary Presentation & Discussion	<p>Presentation Summary</p> <p><u>Presenter:</u> Camara Van Breemen, Nurse Practitioner, and Enhanced Community Care Lead at Canuck Place Children's Hospice, and a Master trainer for the Serious illness Conversation Guide.</p> <p><u>Learning Objectives:</u></p> <ol style="list-style-type: none"> 1. Review the definition of serious illness and the zone of health that can guide advance care planning with seriously ill young adults 2. Reflect on parental journey of caring for a child with complex needs and the transition of care into the adult service 3. Discuss issues of inclusion, competency, shared decision making 4. Discuss the serious illness conversation guide – pediatrics and application of this to this population <ul style="list-style-type: none"> • How do we define “serious illness”: carries a high risk of death over the course of a year (or within childhood – pediatric palliative care), has a strong negative impact on QOL and functioning in life roles, is highly burdensome to a person and their family. • Young adults with medical complexity – considerations: <ul style="list-style-type: none"> - parents are most often the decision makers and may also be long-time, intensive caregivers (which has taken a toll), - parents describe the transition to adult care as being difficult due to a less coordinated or resourced system. - there is minimal ability to transition from pediatric palliative care to adult palliative care because the referral criteria are much more narrow. 	<p>Camara's PPT SLIDE presentation</p>

	<p>Case study of Dylan is shared in the slides – 20-year-old with adrenoleukodystrophy</p> <p>Decision-making and Capacity – a place to start:</p> <ul style="list-style-type: none"> • How does your family make decisions for Dylan’s health care? • Who provides Dylan his day-to-day care? • What do you feel Dylan understands about his condition? • How does Dylan communicate with you about the things he likes or doesn’t like? • Does Dylan prefer to be involved in the meetings about his care or does that bore or distress him? <p>Early conversations about GOC benefit patients and families are associated with:</p> <ul style="list-style-type: none"> • Enhanced goal-concordant care • Time to make informed decisions & fulfill personal goals • Improved quality of life • Higher patient satisfaction • Better patient and family coping • Eased burden of decision-making for families • More and earlier hospice care • Fewer hospitalizations • Improved bereavement outcomes <p>Helpful hints...Critical Experiences</p> <ul style="list-style-type: none"> • Instead of ‘critical abilities’ the question should be framed as ‘critical or essential experiences’ • What are some of the things (experiences) he really enjoys now that you cannot imagine him living without? • What would be 3 wishes you have for Dylan? What do you think Dylan’s are? <p>Helpful hints.... Trade-offs</p> <ul style="list-style-type: none"> • If your child had a setback, what are some things you think may be worth trialing to see if he gets better? What are some things that you feel would not be of benefit or may do harm? • Be prepared to face resistance about trade-off perspectives (many of the children will have had multiple ICU visits that ‘worked’) • Consider ‘end points to medical or treatment trials’ as a way to bridge and keep connection. • “Sounds like going back to ICU for non-invasive ventilation is the care you want. If Dylan does not show recovery after X time, it would be important for us to talk again about things you feel are benefit and things that might not be” <p>Breakout rooms were held with 2 discussion questions presented beforehand:</p> <ul style="list-style-type: none"> • Have you worked with complex young adults in the past? Please share some of your experiences (challenges or rewards). • What are some things you could try and integrate into your practice, if you were meeting with a family who had a young adult with medical complexity and limitations in decision-making/communication? 	
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Session Materials and Additional Resources	<p>Important Resources shared in the presentation:</p> <ul style="list-style-type: none"> • The Representation Agreement Fact sheet breaks down capacity and decision making that can be helpful in determining what types of legal supports/agreements someone may need. It also references and links relevant legislation. • This resource reviews Health Care Consent, including capacity: https://www.nidus.ca/PDFs/Nidus_HealthCareConsent_YourRights-BC.pdf • This resources reviews how health care decisions are made, including if someone is incapable: http://www.nidus.ca/PDFs/Nidus_HowHealthDecisionsMade_ifAdultIncapable-BC.pdf • https://www.ariadnelabs.org/communication-gaps/ • https://bc-cpc.ca/all-resources/hcp-resources/serious-illness-conversations/ • Presenter provided email: cvanbreemen@canuckplace.org 	<p><u>Session Recording</u> is uploaded on the BCCPC's YouTube page:</p> <p>HERE</p>
Closing	<p><u>Next planned SIC ECHO session – Registration opens soon:</u> November 16, 1:00pm - 2:00pm PST</p> <p>“Goals of care conversation needs of community clients facing structural inequities” Presented by Umilla Stead.</p> <p>Visit the BCCPC Palliative Care ECHO website to view all current sessions open for registration and information about our ECHOs.</p> <p>Subscribe: BC Centre for Palliative Care YouTube page</p> <p>Subscribe: BC Centre for Palliative Care Newsletter</p>	<p><u>Post-session Survey:</u></p> <p>HERE</p>